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The Bazelon Center is the leading national legal advocate for adults and children with mental disabilities. Its mission is to protect these individuals' rights to exercise meaningful life choices and to enjoy the social, recreational, educational, economic, political and cultural benefits of community life. The staff uses a coordinated approach of litigation, policy analysis, coalition-building, public information and technical support for local advocates to end the segregation of children and adults with mental disabilities and assure them of the opportunity to access needed services and supports.

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# Teaming Up

### Using the IDEA and Medicaid to Secure Comprehensive Mental Health Services for Children and Youth

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# Teaming Up

# Using the IDEA and Medicaid to Secure Comprehensive Mental Health Services for Children and Youth

Anthony has an extensive family history of serious mental illness. Now 13, he has always had problems in school. He can't read even the simplest material and has explosive outbursts, both at home and at school. He is in a middle school special education program for students identified as emotionally disturbed and has often been suspended for fighting and other disruptive behavior. He spends his reading and math classes in a self-contained classroom, but attends regular art, music and science classes. Anthony loves sports, especially basketball, but the school does not have any recreational facilities. Anthony's worst behavior problems occur in his regular education classes and in the transition between classes, and his mother says she can no longer cope with his behavior at home. After a recent altercation with an older cousin, when Anthony pulled out a kitchen knife and ran barefoot down the street with it, he was hospitalized and treated for psychotic episodes. His former school will not allow him to return. Once Anthony has become stabilized on medication, the hospital wants to release him with a recommendation that he attend weekly outpatient therapy sessions and a therapeutic day program for schooling. Anthony is eligible for Medicaid.

ike Anthony, many children with emotional and behavioral problems do not receive adequate services and supports, if they receive any at all,¹ and most who do, get them through special education.² But these children and youth often need assistance outside of school hours and their families, like Anthony's mother, may also need help in understanding and addressing their child's disability. Two federal entitlement programs—Medicaid and the Individuals with Disabilities Education Act (IDEA)—have the potential, albeit with some limitations, when used together to address these needs for children who qualify for both. They were used thus to resolve Anthony's situation, as described in the example at the end of this document.

When used on behalf of children who qualify for both programs, the two statutes offer an effective way to build the comprehensive and intensive "wraparound" service package now widely understood to be necessary for many children with serious emotional or behavioral problems.

Although Medicaid and the IDEA do not cover identical populations, many children do qualify for both.

- The IDEA is a school-based entitlement, intended to address states' failure to provide educational services to children with disabilities. Services are provided regardless of family income.
- ◆ Medicaid is designed as a health insurance program for low-income children and children with serious disabilities.

Both laws have strong entitlements to services that can benefit children with emotional and behavioral disorders. When used on behalf of children who qualify for both programs, the two statutes offer an effective way to build the comprehensive and intensive "wraparound" service package now widely understood to be necessary for many children with serious emotional or behavioral problems.<sup>3</sup>

Unfortunately, few advocates for children with disabilities utilize either law to its fullest potential. Most lawyers who represent children with emotional and behavioral disorders are familiar with the IDEA, primarily because attorneys can obtain fees when they are successful in litigation. Also, parents and advocates can turn to federally funded Parent Training and Information Centers for resources about the IDEA. So far, however, relatively few attorneys practice Medicaid law, and those who do usually represent children who have physical conditions; they rarely know how Medicaid's provisions apply to children with emotional and behavioral disorders. Most systemic Medicaid litigation has been brought on behalf of children with physical health problems.

This publication is designed to inform practitioners—IDEA attorneys and advocates who are not familiar with Medicaid, and Medicaid attorneys and advocates who do not know the IDEA or who have little experience in using Medicaid—how they may obtain the services and supports needed by children with emotional and behavioral disorders.

The information in this document is particularly timely because both Medicaid and the IDEA are under attack from those who, in the name of maximizing school districts' and states' "flexibility," seek to reduce the number of children served by these programs and to limit the scope of—or even entirely eliminate—these entitlements. Because how these programs can be used together to improve services and supports, it is critically important to protect both programs and to expand Medicaid coverage for children with serious emotional and behavioral problems who are not adequately served through private insurance.

**Teaming Up** explains the benefits and limitations of each program as as highlighted through litigation around the country. Although many of the cited cases are not precedent-setting, they demonstrate how families and their advocates have succeeded (and sometimes failed) in pushing the boundaries of each law to secure the services that children need.

#### What the Two Laws Cover, for Whom

#### The IDEA

The IDEA was originally passed by Congress more than 25 years ago as the Education for the Handicapped Act (EHA). The law entitles children with disabilities to "a free appropriate public education which emphasizes special education and related services designed to meet their unique needs." To accomplish this goal, the IDEA calls for states to implement individualized educational programs (IEPs) for all students who qualify under the law as disabled, including children with emotional disorders. 9

This law has been used to obtain a range of non-academic services needed by children who are identified with "emotional disturbance," including counseling, day treatment and residential care. However, it limits services to those required to assist a child in benefitting from special education —a significant restriction. School districts often use it to deny payment for some services, including room-and-board costs for residential treatment, and to exclude critical family supports, such as respite care and evening and weekend crisis services. Here is where Medicaid can come into play when a child is eligible for it, as a health program that covers many of these services.

#### Medicaid

The Medicaid program (Title XIX of the Social Security Act) provides public health insurance to indigent families and, at state option, to "medically needy" individuals who meet less stringent income criteria. Many children with severe mental or physical disabilities qualify, even when their parents do not, if they qualify for federal supplemental security income (SSI) benefits for children with severe disabilities.

The state pays part of the cost of Medciaid services and the federal government contributes a matching percentage, which varies by state. In exchange for the match dollars, states must comply with the federal law and regulations.

Traditionally, state Medicaid programs have operated on a fee-for-service basis, with providers reimbursed by the state for each service provided to an eligible consumer. Recently, many states have contracted with managed care entities, which instead receive a fixed sum per beneficiary, then contract with providers.

Under either financial mechanism, eligible children have an extremely important right under Medicaid—an entitlement to early and periodic screening, diagnosis and treatment (EPSDT). The EPSDT provision requires a state to provide "necessary health care, diagnostic services, treatment, and other measures ... to correct or ameliorate defects and physical and mental

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illnesses and conditions...." Although states can choose not to provide certain Medicaid services to eligible adults, they must provide all "medically necessary" services to eligible children. The statute also requires states to provide outreach and information to eligible families about their child's entitlement to medical screens to uncover any conditions needing treatment.

The EPSDT statute provides an exceptionally comprehensive entitlement for Medicaid-eligible children. However, implementation of the program is very erratic and, more often than not, Medicaid-eligible children do not receive either the mental health screens or any treatment to which they are entitled. Furthermore, many children are not eligible for Medicaid because their parents' income is too high. Parents' total income is automatically considered available or "deemed" to the child when the child lives in the same household as the parents. <sup>12</sup>

Two federal programs under Medicaid can overcome the parental-income limit for some children who do not otherwise qualify and help them secure in-home or community services: 1) the "Katie Beckett" option<sup>13</sup> and 2) the home- and community-based waiver. <sup>14</sup> These programs should allow many more children to receive comprehensive community-based services.

To take advantage of either, the child must be at risk of hospitalization and the cost of the community-based services provided must be no more than the cost of hospitalization.

Neither approach is mandatory; states must elect the option or apply for the waiver. Unfortunately, while most states have chosen to use options or waivers or both for children with serious medical needs, to date very few employ either approach to serve children with mental or emotional disorders. The Bazelon Center has produced materials explaining the programs in detail and has supported efforts by advocates and policymakers to encourage their states to use the option or waiver. <sup>15</sup>

#### Using the IDEA and Medicaid Strategically

To secure services that are clearly within the school's purview, the IDEA is the obvious first choice for attorneys and advocates representing children with emotional or behavioral disorders. Case law under the IDEA is more developed, while Medicaid litigation on behalf of children with emotional or behavioral disorders is more recent.

Because it is compulsory, school is the ideal venue for identification and intervention. In fact, most children who receive mental health services receive them in school. <sup>16</sup> In addition, children are assured more intensive advocacy under the IDEA—first, by their parents, because the process for developing services and supports also mandates parental participation in almost every key decision. <sup>17</sup> Also, attorneys who prevail in litigation under

the IDEA may receive fees, an important consideration for many solo practitioners, nonprofits, law schools and small firms that must produce incomegenerating litigation to continue their public-interest work.

Even when the services a child needs are not within the school's purview, attorneys and advocates should consider representing parents of children with emotional and behavioral disorders. If a child is already receiving special education services at school, additional services to the family and those sought for the child outside of school hours will probably be better coordinated if they are all part of the same service plan, the IEP. The IDEA ensures that IEP team members will meet at least annually to set goals and review the child's progress. Also, as discussed below, some attorneys have been successful in extending the boundaries of IDEA services—systemically, to require coordination with other child-serving systems, and individually, to access services such as summer programs, recreational activities, and parental and family therapy outside of the school setting.

If the IDEA route is unsuccessful, Medicaid advocacy can be a backup. For access to some services and supports, however, Medicaid is probably the first choice. For example, in-home services and behavior management, so important for children with serious emotional and behavioral disorders, are very difficult to obtain through the IDEA. Attorneys have had some success in obtaining intensive home- and community-based services and supports under Medicaid, particularly for children at risk of hospitalization or other institutional care.

Neither law prevents an attorney or advocate from seeking services simultaneously from both IDEA and Medicaid. Parents and advocates can often obtain Medicaid-covered assessments and services, such as a psychological evaluations and outpatient therapy, more quickly than they are able to secure the same services using the somewhat lengthy process dictated by the IDEA. But the parent may have to travel to a hospital or mental health clinic to obtain services. For reasons of coordination and convenience, parents often want to secure services through the IDEA so that they will be provided to the child in school.<sup>19</sup>

Evaluations obtained using Medicaid are often very helpful for IDEA advocacy. IEP teams must "consider" what the IDEA refers to as "independent evaluations." An outside evaluation can often be obtained more quickly than one requested under the IDEA. It may also be superior to the evaluation conducted by a school district. An outside evaluator presumably has no interest in limiting recommendations about services that the child's school should provide. Because of the disparity in pay, prestige and working conditions, hospital- and/or university-affiliated evaluators often have better credentials than evaluators in school districts and may take more time to evaluate a child. Sometimes, too, independent evaluators may agree to

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appear as witnesses in IDEA due process hearings when eligibility or necessary services are contested by school districts. <sup>21</sup> Prior to obtaining an independent evaluation, attorneys and advocates may want to ask potential evaluators about their availability and willingness to testify should the special education advocacy become contentious.

The following sections will describe both successful and unsuccessful uses of the IDEA and Medicaid to obtain necessary services and supports for children who have emotional and behavioral disorders.

#### Using the IDEA for Access to Mental Health Services

#### **Class Actions for Systemic Change**

Advocates have brought lawsuits under the IDEA to compel school systems to coordinate with other state agencies in providing an array of mental health services, often using class actions to address system-wide deficiencies. Perhaps the best known of these is *Willie M.*, a suit filed more than 20 years ago in response to a crisis in North Carolina's juvenile court system. <sup>22</sup> Judges and lawyers were increasingly frustrated by the lack of treatment alternatives for violent and assaultive youth with emotional disorders, and advocates brought claims under the Fourteenth Amendment, the IDEA and state law. A landmark settlement of the litigation mandated individualized services planning with an emphasis on family-based care for children with serious emotional disorders.

Now, as then, the vast majority of the children affected by this lawsuit are adjudicated through the juvenile justice or child welfare systems. The relief provided is not a preventive program or one designed to keep children out of state custody. <sup>23</sup> However, unlike many children in state custody, those in the *Willie M.* class receive comprehensive mental health services and supports. In fact, the state has been so successful in building a system of care for these children that a district court dismissed the action in 1998. <sup>24</sup>

Subsequent class actions have sought an integrated approach to a state's services for all children with serious behavioral health needs served by the public sector. Most have relied on other constitutional and statutory provisions, but one, in Hawaii, invoked the IDEA and Section 504 of the Rehabilitation Act. The suit claimed that the state had failed to provide required educational and mental health services to eligible children. The court found the state liable, largely on the basis of its own admissions as to the inadequacies of services. The order was followed by a consent decree jointly drafted by the attorneys for the children and the state, which included:

- ◆ a set of operating principles and standards to guide the system;
- ♦ timelines for developing more specific implementation procedures based

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- on these standards;
- agreement by the Department of Education to provide all educational services needed by the plaintiff class and by the Department of Health to provide all of the mental health services the children required to benefit from those educational services; and
- appointment of a monitor to assess progress and assist with implementation.

Such system-reform cases inevitably require intensive advocacy over a long period. The parties in the Hawaii class action developed an elaborate implementation plan, including establishment of community children's councils to foster local integration of services and involvement in planning. Four years later, after the state had failed to comply, the parties agreed to and the court approved 141 benchmarks by which the state's compliance was to be monitored. A year later, although the state had complied in some areas, the court found that it had failed to take "every reasonable step" to comply with the decree and held the state in contempt. <sup>26</sup>

After the contempt finding, the state made greater efforts to comply with the decree. In 2002, the court found the state was in substantial compliance with the consent decree in most areas. This moved the litigation into a "sustainability" phase, which required the state to provide evidence it was maintaining compliance. The court and the plaintiffs' attorneys are currently receiving quarterly reports on the various performance indicators the state has to meet. Although the performance-indicators requirement expires at the end of 2003, the state will remain subject to the court's jurisdiction. A monitor has also been appointed to ensure compliance and to attend to the areas where the defendants are not meeting performance indicators.

The IDEA has also been used successfully to address one of the most common barriers to special education services, the long delay between the time children are identified as needing special education services and when they can access the services—especially private school placements, when the public system lacks appropriate programs. Parents and guardians in Pennsylvania who brought such a case told of children with emotional disturbance stuck for months at home or in inappropriate placements. The compelling facts—children's deteriorating mental conditions, high fees for public services, parents' having to relinquish custody of their children to obtain mental health services, and the lack of appropriate, less restrictive public programs—convinced the court that the children were being deprived of the education to which they were entitled by law. The court ordered the state educational agency to develop additional public and private placements.<sup>28</sup>

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#### Individual Claims for Out-of-School Mental Health Services

Although IDEA cases have been successful in obtaining school-based mental health services,<sup>29</sup> many children with serious emotional and behavioral disorders require more comprehensive interventions, including inhome services and recreational programs. The class actions discussed above invoked the IDEA in combination with other federal and state laws to seek a comprehensive set of services for a class of children. For individual children, however, before proceeding to other claims,<sup>30</sup> advocates often explore use of the IDEA alone to access out-of-school mental health services.

#### (1) Parental and family therapy outside of the school setting

Hearing officers and administrative law judges (ALJs) routinely require schools to provide counseling to students as a related service and to reimburse parents for their child's private counseling when the school district's program is found inadequate. For example, a school in Pennsylvania was ordered to reimburse parents for private behavior intervention therapy because its services were not well-defined, did not take into consideration the child's need for continuity and were not individually tailored to the child's educational needs.<sup>31</sup>

The IDEA explicitly contemplates that schools will provide "counseling and training" to parents of children with disabilities to help them understand their child's disability and better assist the child in school.<sup>32</sup> It is far less common, however, for schools to be required to provide therapy to the family or the parents outside of the school setting.

Decisions on this topic are mixed. They generally depend on whether it has been established that the counseling is necessary for the child's educational progress. A California school district was required to fund the entire cost of parental counseling while the student was in an out-of-state residential placement because counseling was necessary for the child to benefit from the educational placement.<sup>33</sup> But a Massachusetts decision went the other way, holding that the parents of a 15-year-old with post-traumatic stress disorder, depression and learning disabilities were not entitled to private family counseling because counseling addressed family issues, not school matters.<sup>34</sup>

The IDEA does not limit services to those provided by or through the school system. Parents may seek reimbursement for services obtained privately if a school does not offer an adequate option as part of a student's IEP. <sup>35</sup> The Sacramento, California school district, for example, was obligated to reimburse parents for individual and family counseling because school officials knew that the student needed such counseling to benefit from his education and yet failed to provide it.<sup>36</sup>

Hearing officers and administrative law judges routinely require schools to provide counseling to students as a related service and to reimburse parents for their child's private counseling when the school district's program is found inadequate.

#### (2) In-home services and behavior management

In-home behavioral health services are an important element in a system of wraparound services for children with emotional disorders. So far, Medicaid appears the preferred route to advocacy for these services because no order under the IDEA that a school district pay for them has yet held up. For example, in a case where an ALJ awarded additional occupational, speech and language therapy, an extended day program and an at-home behavioral management program designed by an experienced psychologist, the district court upheld the added speech and language therapy but declined to rule on the other services.<sup>37</sup>

A court in Washington rejected the parents' request for an attendant at their house before and after school for a blind, quadriplegic student who was experiencing psychosis because of uncertainty about his environment.<sup>38</sup> The student was given an attendant only for school hours and on the bus. And in Connecticut, a hearing officer ruled that the school district was not required to provide a mentor to supervise study at home and in the community because this was not considered an educational support service.<sup>39</sup>

Cases for children with autism and other developmental disabilities are mixed. In a Massachusetts case, the school was ordered to provide 10 to 15 hours of in-home applied behavioral analysis training. <sup>40</sup> But the Fourth Circuit held that in-home behavior management services were not necessary to achieve an educational benefit when the student had showed progress without them and when such services were the responsibility of the state department of human resources. <sup>41</sup> However, a hearing officer in Illinois ordered the school to provide in-home "transitional services," such as counseling and occupational and physical therapy, to enable a student to move from home schooling to public school. <sup>42</sup> And an Indiana school district, at a parent's request, was ordered to provide an aide before and after school to help with transportation and coordinate a behavioral management plan to transition the student from home to the school environment. <sup>43</sup>

Because hearing officers and courts have been reluctant to hold schools responsible for providing in-home and behavior management services, attorneys and advocates must make a strong case that these services are necessary for educational purposes. Securing the services of an expert who can present such evidence seems absolutely necessary if such a claim is to have any chance of success.

#### (3) Recreational activities outside of school

The few decisions on recreational activities suggest that hearing officers and judges are less concerned about individualizing these services, perhaps because they were not convinced of the services' therapeutic and educational benefits. Parents have been unsuccessful in seeking recreational services when the school provides some alternatives, even when the alterna-

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For example, a court in California held that a high school student with emotional disturbance who sought physical release through a boxing and weight-training program did not require these services to benefit from his education because the school provided other sports and physical education classes, even though the child was not interested in them. <sup>44</sup> And a Connecticut decision held that a student with a physical disability was not entitled to a horseback-riding program because the school's physical therapy program was deemed adequate. <sup>45</sup>

However, a Massachusetts school district was forced to reimburse the parents for an after-school program at the local Boys and Girls Club for a student with post-traumatic stress disorder, depression, bipolar disorder and behavioral problems because the school did not provide an adequate after-school program to address the student's needs on school days.<sup>46</sup>

#### (4) Extended-year services

The IDEA regulations call for districts to provide extended-school year (ESY) services whenever they are determined necessary for a special education student. <sup>47</sup> However, the standard for a student to qualify for extended-year services is stricter than the standard for qualifying for special education services during the school year. The Department of Education expressly allows state educational agencies to determine the precise standard for ESY qualification. <sup>48</sup> As a result, various standards have been established by judicial precedent, including a likelihood of academic regression during periods when schools are closed, slow recovery of skills or professional predictions that the child's education will suffer. <sup>49</sup>

Cases show that the stricter standard for ESY services often leads to denial of services such as in-home behavior management, family therapy and recreation outside of school during the summer, even when those services are provided during the school year. For example, a reviewing officer upheld a New Jersey school district's denial of payment for summer performing arts camp for a student with multiple academic and social disabilities who was entitled to ESY. <sup>50</sup> The decision noted that the primary function of ESY is to prevent a student's reversion to a lower level of functioning, not to help her self-esteem.

However, in some cases students have overcome the higher standard even when the summer service is not academic in nature. A Massachusetts school district was ordered to pay for a student with oppositional disorder and low self-esteem to attend recreational day camp.<sup>51</sup> And in California, a school district was ordered to provide transportation for 13 students with emotional disorders to and from their counseling services between the end of ESY services and the start of the school year because without continued counseling the students risked regression and irreparable harm.<sup>52</sup>

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#### Coverage of Residential Treatment under the IDEA

Parents seeking residential treatment often find their private insurance inadequate, so they turn to the IDEA and Medicaid to fund this expensive care. <sup>53</sup> The cases in this area appear mixed, with parents having to surmount many legal hurdles to seek coverage for residential services under the IDEA. When they are unsuccessful, some turn to the child welfare system. Far too often, parents whose child is not eligible for Medicaid must relinquish custody of the child to obtain residential services paid for by the state. <sup>54</sup>

When seeking residential services for a child, parents must meet both prongs of a two-prong test. <sup>55</sup> First, they must establish that the child's IEP does not meet the standard set by the U.S. Supreme Court in 1982 in its *Rowley* decision—that the IEP be "reasonably calculated to enable the child to receive educational benefits." <sup>56</sup> Then the parent must demonstrate that the proposed placement is appropriate.

Most cases do not reach the second stage because the *Rowley* standard is fairly easy for school districts to meet. For example, the 10th Circuit upheld a decision denying a residential placement for a student who met some, but not all, of her IEP goals,<sup>57</sup> and a district court in Kansas found no support for residential placement when a student is "progressing academically, engaging in no violent behavior at school, and functioning on par with his grade level academically."<sup>8</sup>

If the case does reach the second stage, "appropriateness" must be shown. A California court described three possible tests to determine the appropriateness of residential placement: "(1) where the placement is 'supportive' of the pupil's education; (2) where medical, social or emotional problems that require residential placement are intertwined with educational problems; and (3) when the placement is primarily to aid the student to benefit from special education."<sup>9</sup>

#### The student's history in a day program

Successful cases tend to document a child's serious school failure in a day program prior to the residential placement and subsequent progress in the residential setting. <sup>60</sup> In the California case mentioned above, the student was hospitalized after she attacked her mother and broke windows in an outburst over a homework assignment. Her behavior worsened during the next four placements in day programs—including incidents of criminal behavior and attacks against family members—and culminated with another hospitalization. At the administrative level, the hearing officer concluded that there was "'simply no evidence to establish that [the student] made any progress toward the goals in her IEP.'"<sup>61</sup> The facts were so strong that the court found a residential placement appropriate under any of the three tests.<sup>62</sup>

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The court concluded that the "fact that a residential placement may be required to alter a child's regressive behavior at home as well as within the classroom, or is required due primarily to emotional problems, does not relieve the state of its obligation . . . so long as it is necessary to insure that the child can be properly educated."

A somewhat less dramatic example is a Connecticut case in which a mother, Mrs. B., sought reimbursement for the educational expenses of residential placement for her 17-year-old daughter, who had been diagnosed with learning disabilities and serious social and emotional problems. (The noneducational expenses were already being paid by the Department of Child and Youth Services, which had placed the child.<sup>63</sup>) The student's "history in the public school [prior to her residential placement] . . . was marked by very limited academic progress, and serious regression in the year prior to placement."<sup>64</sup> The court concluded by noting that the "fact that a residential placement may be required to alter a child's regressive behavior at home as well as within the classroom, or is required due primarily to emotional problems, does not relieve the state of its obligation . . . so long as it is necessary to insure that the child can be properly educated."<sup>65</sup>

At least one circuit has held that a school district does not have to try a day program and require student failure before having to fund a residential placement. A Seattle, Washington student was first referred for an evaluation in 1990. Although she exhibited serious behavioral problems, the district's professionals did not classify her as entitled to special education services under the IDEA, but instead undertook interventions that proved ineffective. In December 1992, when the student "became so verbally and physically assaultive that she was placed in restraints and taken to [the hospital]," the school expelled her. <sup>66</sup> The student remained out of school for the rest of the year and was not reevaluated until five months after the expulsion. The school provided no educational services for six months until ordered by an administrative law judge (ALJ) to provide tutoring, and later a residential placement. <sup>67</sup> The parents prevailed again, both in the district court and on appeal.

The appellate court rejected the school district's arguments that it was being held to a standard higher than *Rowley* or that a residential placement violated the provision of the IDEA that children with disabilities be educated in the least restrictive environment (LRE). The court concluding that the IDEA "does not require [a student] to spend years in an educational environment likely to be inadequate and to impede her progress simply to permit the School District to try every option short of residential placement." <sup>68</sup>

Parents seeking a residential placement often face the challenge made by the Seattle school district, that they are attempting to avoid mainstreaming or to get around the LRE preference in the IDEA. <sup>69</sup> Sometimes that argument prevails. A Maine court, for example, denied a residential placement even though the parents provided evidence that their eighth-grader was making little or no academic progress. <sup>70</sup> The court found that "a student 'who would make educational progress in a day program' is not entitled to a residential placement even if the latter 'would more nearly enable the child to reach his or her full potential.'"<sup>71</sup>

#### Stigma and blame

Caregivers of children with psychiatric disabilities also must surmount the stigma and blaming associated with these disabilities. Although the appellate court in Mrs. B's case, discussed above, found in favor of her daughter, the administrative decision contains some disturbing language that reveals continuing bias about children with emotional and behavioral problems. The hearing officer denied reimbursement for the residential placement, reasoning that "where predominantly and significantly the child's problems grow out of the home situation rather than the school environment, the school cannot be taken to task" and concluding that the child was responsible for her own failure to learn.<sup>72</sup>

Parents in a New York case faced similar attitudes by the hearing officer when they sought reimbursement for a private day program for their child with serious emotional problems. Although the parents ultimately prevailed on appeal, the hearing officer ruled against them, concluding that the girl's problems were the result of "family issues."<sup>73</sup>

A finding of delinquency increases the likelihood that parents will be denied reimbursement for a residential placement using the IDEA. Parents in Missouri were denied reimbursement because the judge concluded that the reason for initiating the residential treatment—an assault on another child—was "psychological," not educational.<sup>74</sup> The ruling did not take into account that the student's first incident of violent behavior occurred at school, when he threatened to kill a teacher. The judge appeared to rely heavily on the family court's adjudication of delinquency and its placement of the student in the residential facility pursuant to the delinquency finding.

Creating a detailed factual record that includes the emotional costs to families and children may be helpful in combating this stigma. In the District of Columbia the parties made the court aware that a denial of services would lead to custody relinquishment. The court relied heavily on the testimony of the child's treating physician, who stated that "a neglect proceeding in Superior Court would have a devastating impact on plaintiffs' course of treatment." The physician also testified that the child's disability had been exacerbated by his perception that his parents had abandoned him. The court was influenced by "the unrefuted medical opinion ... that the stigma of having his parents adjudicated neglectful and unwilling to care for him would seriously cripple efforts to deal with his problems and to reunite his family." Based on this testimony, the court ordered the school district to pay for residential treatment.

Caregivers of children with psychiatric disabilities also must surmount the stigma and blaming associated with these disabilities.... Creating a detailed factual record that includes the emotional costs to families and children may be helpful in combating this stigma.

# Medicaid Cases Seeking Access to Comprehensive Services

Advocates have only recently begun to use Medicaid's EPSDT entitlement to address behavioral health needs, and most of the cases have settled or are currently in litigation. Accordingly, only a few decisions have been issued so far on access to comprehensive behavioral health services under Medicaid.<sup>77</sup> Three important cases have addressed the lack of such access in fee-for-service programs,<sup>78</sup> and several more suggest that Medicaid has a powerful role to play in holding managed care systems accountable for serving children with emotional disorders appropriately.

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#### **Fee-for-Service Programs**

One of the first challenges to a state's failure to comply with the EPSDT entitlement for mental health services is the story of Larry, 8, who had attention deficit hyperactivity disorder and conduct disorder and was confined to a mental hospital because the state refused to pay for residential treatment. The complaint noted that if Larry's parents turned their child over to the foster care system, his care would be funded. But his parents did not want to relinquish their parental rights and responsibilities and sued the three relevant state agencies.

The case settled out of court when the state agreed that the Medicaid program would pay for medically necessary residential treatment and wraparound mental health services for children and adolescents. This means coverage of virtually any in-home support and therapy, counseling or clinically supervised activity that is designed to keep children with behavioral disorders at home or in a community setting.

The settlement also addressed the underlying problem that Pennsylvania, like many states, did not include several needed services in the state Medicaid fee schedule. As a result, providers had no way to bill for reimbursement and the services were unavailable, even though children were entitled to them under the EPSDT mandate. The settlement provided that the Department of Public Welfare would issue bulletins explaining to providers the requirements and procedures to be reimbursed for a comprehensive array of mental health services. The department issued two bulletins:

- ◆ The first added important wraparound services to the fee schedule and specified the procedures for receiving payment.
- ◆ The second clarified the procedures for residential treatment facilities to qualify for payment.

The additional list of home and community services included: mobile therapy, therapeutic staff support, behavioral specialist consultant, individual diagnostic personality evaluation, comprehensive neuropsychological

evaluation, cognitive retraining and psychological evaluations.

Building on the Pennsylvania experience, advocates in California filed a case seeking similar relief—a procedure for and the actual provision of home- and community-based wraparound services. <sup>80</sup> The plaintiffs were children with intense mental health needs who were placed in or being considered for placement in a psychiatric facility or who have had at least one emergency hospitalization. They sought wraparound services such as behavior management services, a one-on-one therapeutic aide, attendant care, crisis intervention, case management and transportation assistance.

The court issued a preliminary injunction, finding that the two state agencies were required under Medicaid law to provide "preventive and rehabilitative services" to children and that "therapeutic behavioral health services could be considered both preventive and rehabilitative as contemplated by the statute." Noting that the state had voluntarily opted into the federal Medicaid program, the court ordered the state to implement procedures for the plaintiffs to request and access therapeutic behavioral services and to inform class members about the procedures. On March 30, 2001, the court issued a permanent injunction. The case has helped to educate state and local officials about the scope of the mental health entitlement in EPSDT.

In addition to building on prior work in Pennsylvania, the California attorneys relied on a successful class action in Maine, brought on behalf of Medicaid-eligible children who needed home-based mental health services but could not obtain them because the state agencies provided insufficient funds to match the federal share. <sup>83</sup> In addition, the state refused to provide any coverage for personal care-attendant services, failed to provide sufficient reimbursement to recruit and retain qualified providers of home-based services, and used an assessment tool that was not designed to evaluate episodic mental impairments. Many of the children were on a waiting list for home- and community-based waiver services, but in the meantime received no services.

As occurred in the California case, the plaintiffs moved for preliminary relief to get immediate help in obtaining services and the state entered into negotiations to avoid a trial. Negotiations were successful, and the case settled. The state agreed to issue new rules and regulations so that children with behavioral health needs and mental retardation receive:

- timely case management services;
- the presumption of medical necessity for services developed in a treatment plan by a provider after an assessment;
- prompt services, generally provided no later than six months after the date an assessment was requested;
- services which are not denied or delayed based on lack of seed money;
- ◆ a resource directory of services for case managers and the state's best efforts to develop additional resources where needed; and

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• removal of the annual cap on day habilitation services.

Other provisions of the agreement address outreach, screening, provider training, monitoring and quality improvement, and include the outline of a comprehensive state plan for the provision of mental health services. The parties recently renegotiated a settlement.

#### **Reforming Medicaid Managed Care Systems**

The advent of managed behavioral health care has added a new dimension to litigation of EPSDT claims. Two statewide class-action lawsuits for children in managed care have initiated overall reform of state mental health systems for children.

Arizona is one of the oldest statewide managed care systems, having refused to join the Medicaid program until it was allowed to do so under managed care. A lawsuit was filed in 1991, alleging that some 20,000 Medicaid-eligible children identified as needing mental health services were not receiving them as required by EPSDT. <sup>84</sup> The state's first response was to deny responsibility for the program because it had contracted with private entities for the provision of services. The district court flatly rejected this argument, holding "it is patently unreasonable to presume that Congress would permit a state to disclaim federal responsibilities by contracting away its obligations to a private entity." <sup>85</sup>

After this early decision, the parties began an extended discovery process. A December 1997 interim settlement agreement required the state to appoint an independent expert panel to study whether children in Maricopa County (the Phoenix area), home to half of all class members, were receiving medically necessary mental health services. The study, directed by a nationally recognized children's mental health expert, found that more than half of the children were not receiving necessary care and confirmed that children were being forced into state custody because of the mental health system's failures.

Ultimately, after a second expert report documented continued failings, a new settlement was negotiated and signed in March 2001, based on 12 key principles for the delivery of mental health services to children.<sup>87</sup> The results of a pilot program have received favorable reviews.<sup>88</sup> The history of this case illustrates the value of studies conducted by independent experts, which can provide objective evidence to state policymakers, help educate community stakeholders and galvanize interest in changing the status quo.

Settlement of a second EPSDT class action, in Tennessee, also required independent studies documenting the managed care provider's failure to provide outreach, screening and treatment for both physical and mental conditions to Medicaid-eligible children in the state's foster care system. <sup>89</sup> The state, as a result of the suit, amended its managed care contracts to

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include a minor financial penalty for managed care entities whose refusal to provide necessary services leads to custody relinquishment to the state. However, the amendment failed to address the overall lack of adequate services, and the state did not submit an adequate remedial plan to address the studies' findings and refused to comply with consent decrees.

Following a trial, the court held in December 2001 that the state's managed care system had failed to adequately meet EPSDT requirements mandated by federal law and the consent decree. The court ordered the state to carve out the under-21 population from the larger pool of managed care recipients and appointed a special master to facilitate implementation of an EPSDT- compliant state Medicaid plan for the youth population.

#### Challenging Managed Care's Denial of Mental Health Services

Individual cases have also been brought on behalf of children denied appropriate mental health services by Medicaid managed care plans. In at least one, a Tennessee case, attorneys have directly sued the managed care entity that failed to provide needed mental health services.

Christopher B., 15, has autism, developmental delays, Tourette's syndrome, major depression with psychotic features, and post-traumatic stress disorder (PTSD). When Christopher appeared suicidal, his mother had to wait 10 hours for the managed care plan to approve his hospitalization. While she waited, her son grew violent toward her and incessantly repeated that he wanted to end his life. Christopher finally entered the hospital. But a few days later, Mrs. B. was called and told to pick him up because he no longer needed acute care. The staff readily acknowledged that he needed residential treatment, but said it was his mother's responsibility to find the treatment.

Mrs. B called a representative from the managed care company, who then told her to have the hospital call. That same night, she went to visit Christopher and found him very upset. The doctor informed her that her son had been sexually victimized by a roommate the night before. Although the staff knew that Christopher had been diagnosed with PTSD as a result of prior sexual abuse in a hospital, they had put him in an unsupervised room with a roommate.

The next day, the managed care company finally certified Christopher for residential treatment, but they limited the authorization period to one day. The hospital could not get any center to take him with such a short authorization period. Hospital staff threatened Mrs. B. that if she did not pick up her son, he would be placed in state custody due to abandonment. After an attorney intervened, the hospital agreed to keep him for further evaluation but they told Christopher that his mother refused to pick him up so he could not go home. With this news, he went out of control, screaming

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In Christopher B.'s case, the managed care company has agreed to pay for a residential treatment facility specifically designed for children with co-occurring developmental disabilities and serious emotional disturbance, and is planning to contest the school district's failure to pay the educational part of the placement.

that he hated his mother and never wanted to see her again. The hospital kept him for six more weeks before he began a series of moves from placement to placement without an adequate assessment or proper discharge planning.

The complaint includes contract, tort (negligence, outrageous conduct/intentional infliction of emotional distress), consumer protection act, due process and Medicaid EPSDT claims. <sup>91</sup> The case is in litigation and will be closely watched as one of the very few to challenge private managed care companies' inadequate provision of behavioral health services.

Even when facts are as compelling as these, plaintiffs have faced the problem of determining whom to sue because managed care entities frequently subcontract to have some services provided by other organizations. With these complex corporate relationships, it is easy for companies to avoid accepting responsibility. In Christopher B.'s case, the managed care company has agreed to pay for a residential treatment facility specifically designed for children with co-occurring developmental disabilities and serious emotional disturbance, and is planning to contest the school district's failure to pay the educational part of the placement. These developments may provide an opportunity for settlement.

An individual action in Pennsylvania, brought to secure both mental and physical health services for children and adults, offers strategies for monitoring denials and preventing arbitrary rejection of service requests. The settlement agreement includes a mechanism for plaintiffs' attorneys to review copies of all notices of denials, reductions and terminations of services by the managed care entity and a requirement that the state conduct a random review of 10 percent of these notices at least every three months. The Pennsylvania agency also is required to conduct a random telephone survey to determine whether the HMOs are verbally denying claims without giving plan members or their families written notice of their decisions. Another useful provision is the requirement that an individual's case manager cannot also have responsibilities for reviewing requests for outpatient services.

#### Using the IDEA and Medicaid Together— An Example

Anthony's situation—hospitalized and rejected by his school because of his behavior, as described at the beginning of this paper—offers an example of steps that advocates can take to coordinate Medicaid services and education-related services under the IDEA.

#### Challenge the hospital's recommendation.

First, the hospital's recommendation for Anthony's discharge plan should be challenged. On a common-sense level, it seems unrealistic that he can transition successfully from round-the-clock care to a day program with only weekly outpatient counseling. When Anthony's advocate engaged the social worker in a conversation about the proposed discharge plan, it became apparent that the plan was based on services the social worker knew existed, not on what was medically or educationally necessary for Anthony.

#### Obtain an individualized discharge plan.

Advocacy should lead to an individualized discharge plan that is specific about what the educational program should include (e.g., intensive assistance for reading disorder, not just therapy) and a treatment plan based on what is "medically necessary," not just what a psychiatrist or social worker knows is available. Taking such an approach, the discharge plan might include in-home therapy, three times weekly for Anthony and once a week for his mother and siblings, with a recommendation that the therapist also be in contact with Anthony's school to coordinate his treatment. The plan might also call for a recreational program, such as basketball, to help Anthony build self-confidence and learn to socialize with his peers without fighting. Such detailed documentation is critical to securing services through both the IDEA and Medicaid.

#### Pursue a therapeutic day program.

A therapeutic day program with services that address Anthony's learning difficulties should be pursued through the IDEA. There is ample evidence in his school record that he is unable to benefit educationally in classes that are not part of a therapeutic setting. His advocate could argue that the recreational activity should also be provided by (or paid for by) the school. Anthony's inability to interact constructively with his peers has severely impaired his ability to benefit from educational services. If the school offers a recreational program other than basketball that would still provide the socialization benefits he needs, Anthony may have to accept. However, Anthony's advocate should emphasize the IDEA's mandate for individualized services to argue that the recreational activity should match

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Anthony's interest and abilities. To be a reimbursable service under Medicaid, the recreational activity must be more clearly defined as therapeutic recreation and/or social skills training.

#### Design a program of in-home therapy services.

In-home therapy services are much more likely to be obtained through the EPSDT provisions of Medicaid. Counseling is a typical Medicaid service, although providing it in the home must be determined medically necessary.

The advocate should elicit more detail from Anthony's treating psychiatrist to determine the purpose of in-home services. For many children and youth, therapy can be more effective if it takes place in the setting where they are having behavioral problems. In addition to making the child more comfortable, the therapist can observe the family dynamics and intervene to address behaviors as they occur. With teenagers, in-home therapy may make them more likely to participate.

One could also argue that the family therapy is a related service under the IDEA, depending on its purpose. If the therapy sessions are meant to help the family understand Anthony's disability and improve their interactions with him—and this assistance will help him benefit from his educational services by, for example, enabling him to complete his homework and attend school more regularly—then the IDEA may cover the service. This is a case in which the advocate may choose to pursue services through both Medicaid and the IDEA to see which route is successful sooner.

Utilizing both Medicaid and the IDEA, the advocate can increase the chances of obtaining a more comprehensive package of mental health services than Anthony would receive through either entitlement alone.

# Utilizing both Medicaid and the IDEA, the advocate can increase the chances of obtaining a more comprehensive package of mental health services than a child would receive through either

entitlement alone.

#### Conclusion

The IDEA provides an important entitlement to educational services for children with serious emotional disturbance and is a useful tool for securing school-based mental health services such as attendant care, counseling and other supports. It has the added benefit of serving children where they are—at school. This broad entitlement, however, has several major limitations.

First, services are limited to those that provide some educational benefit. Case law indicates that judges tend to use the school day as a proxy for educational benefit, so that services before and after school or in the home are often rejected.

Next, residential services are only available after surmounting several legal hurdles and are most often awarded in response to egregious neglect by a school district.

Finally, parents have the extra burden of battling the stigma and nega-

tive attitudes associated with psychiatric disabilities, particularly in a climate where schools are fixated on potential violence or disruption and zero-tolerance policies proliferate.

Although Medicaid claims can work only for children who are eligible for the program, the EPSDT requirements remain one of the strongest entitlements to behavioral health services. Advocates are just beginning to realize the potential of this statute to generate intensive and comprehensive community-based mental health services. The cases that have been litigated offer guidance on how to work with state agencies to expand access to services through administrative changes and how to use independent studies to galvanize change. For Medicaid-eligible children and youth, EPSDT can fill in gaps left by the IDEA.

Attorneys and advocates working with families of children and youth with emotional and behavioral disorders should become familiar with the benefits and limitations of both the IDEA and Medicaid. Using these strong entitlements together can produce more intensive and comprehensive mental health services for children and youth who need them. Better prevention and intervention services can reduce the need for traumatic and disruptive hospitalizations and long stays in residential treatment facilities.

#### **NOTES**

- 1. U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General*, Chapter 3 (1999), www.surgeongeneral.gov/library/mentalhealth/home.html (herinafter Surgeon General's Report). According to the Surgeon General's report, 75-80% of children with mental health issues fail to receive the help they need.
- 2. *Id.* Seventy percent of children with mental health issues receive treatment in school, 40% receive services from the mental health system, 16% from child welfare, 11% from the health care system, and 4% from juvenile justice. (The percentages total more than 100% because some children receive services from more than one system at a time.) For half of the children, school is the sole source of mental health treatment. *Id.*
- 3. Lourie, I.S., Katz-Leavy, J. & Stroul, B.A., Individualized Services in a System of Care, in B.A. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society*, Baltimore MD: Paul H. Brookes Publishing Co, 1996; Rosenblatt, A., Bows and Ribbons, Tape and Twine: Wrapping the Wraparound Process for Children with Multi-System Needs, *Journal of Child and Family Studies*, 5, 1, 101-117, 1996.
- 4. 20 U.S.C. §1415(i)(3)(B).
- 5. 20 U.S.C §1482. A directory of the centers can be found at the website of the Technical Assistance Alliance for Parent Centers, www.taalliance.org.
- 6. See e.g., *Frew v. Gilbert*, 109 F. Supp.2d 579 (E.D. Tex., 2000) (Class consisting of poor children sought enforcement of consent decree resolving suit claiming that State of Texas did not adequately provide medical and dental care to poor children under Medicaid Early Screening, Diagnosis and Training program (EPSDT)).
- 7. Congress is currently taking up legislation to reauthorize the IDEA. The version passed by the House of Representatives, H.R. 1350, would allow schools to unilaterally suspend or expel students who have violated any school "code of conduct." The Senate version maintains

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the mandate that a school consider the impact of a disability on the child's conduct but weakens the requirement of a behavioral assessment. See Bazelon Center *Action Alerts* of April 24, 2003 and July 9, 2003. Medicaid has been targeted by both the Administration for conversion from an entitlement to a capped grant program. See Bazelon Center *Action Alert* of May 5, 2003. All Bazelon Center Action Alerts are available at www.bazelon.org/takeaction/alerts.

- 8. 20 U.S.C. § 1400(c).
- 9. 20 U.S.C. § 1401(a). Some states have expanded the definition of "emotional disturbance" and serve a broader group of children than required by the federal law. Conversely, students with serious emotional problems often do not receive the services to which they are entitled because states' narrowly interpret the federal definition or for other reasons. For more information on this topic, see the Bazelon Center's Issue Brief, *Failing to Qualify: The First Step to Failure in School?* (January 2003)
- 10. 42 U.S.C. § 1396(r)(5).
- 11. See National Health Law Program, Executive Summary, Children's Health Under Medicaid: A National Review of Early, Periodic Screening, Diagnosis and Treatment, August 1998 (noting that of the 22.9 million EPSDT- eligible children in 1996, only 37% received a medical screen). See Bazelon Center for Mental Health Law, Where to Turn: Confusion in Medicaid Policies on Screening Children for Mental Health Needs (September 1999) and Semansky, R., Koyanagi, C., and Vandivort-Warren, R., Behavioral Health Screening Policies in Medicaid Programs Nationwide, Psychiatric Services 54:2, May 2002, p. 736.
- 12. Under the deeming rules, an institutionalized child is no longer considered to be living with his or her parents after the first full month of institutionalization; after one month, only the child's income is considered in determining eligibility for SSI and thus, Medicaid.
- 13. The "Katie Beckett" option was originally a waiver program designed as a response to the plight of a technology-dependent child who was required to reside in an institution in order to qualify for Medicaid and receive medical services. Her parents' income exceeded Medicaid guidelines, but was insufficient to pay for her extensive health care needs. The program was converted into an option, known as the TEFRA 134 option because it was enacted under section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (P.L. 97-248).
- 14. This waiver, codified at 42 U.S.C. § 1396n(c), is designed to cover the cost of home- and community-based services for individuals who without such services, would require hospitalization services, which would otherwise be reimbursed by Medicaid.
- 15. Bazelon Center for Mental Health Law, Avoiding Cruel Choices (November 2002) and An Advocate's Guide to Overcoming State Barriers and Obtaining a Home- and Community-Based Waiver for Children with Mental Health Needs. Both are available online at www.bazelon.org/issues/children and hard copies of both are available for purchase through www.bazelon.org.
- 16. Surgeon General's Report.
- 17. See, e.g., 20 U.S.C. §1414, requiring informed parental consent before evaluations and reevaluations, parental participation in IEP team, and parental participation in all education-placement decision making.
- 18. 20 U.S.C. §1414(d)(4)(A)(i).
- 19. For Medicaid-eligible children, the school can often seek reimbursement for Medicaid services. 20 U.S.C. §1412(a)(12). Although this is an important source of revenue for states, parents and their attorneys and advocates need only be aware for strategic purposes that schools have such opportunities.
- 20. 20 U.S.C. §1415(b)(1).
- 21. Although Medicaid covers the cost of the evaluation, the evaluators may require a fee for their time preparing and testifying for a due process or court hearing.
- 22. Willie M. v. Hunt, No. CC-79-294 (W.D.N.C. 1980)(consent decree); see also Willie M. v. Hunt, 657 F. 2d 55 (4th Cir. 1981).

- 23. For a detailed discussion of this lawsuit, see Soler, M. & Warboys, L., Services for Violent and Severely Disturbed Children: The Willie M. Litigation, in Sheryl Dicker, et al, *Stepping Stones: Successful Advocacy for Children* 61 (1990).
- 24. No. 3:79-CV-294-MU (W.D.N.C. Jan. 22, 1998)(order terminating class action).
- 25. Felix v. Waihee, No. 93-00367DAE (D. Haw. May 24, 1994)(on file with authors).
- 26. Felix v. Cayetano, 32 I.D.E.L.R. 230 (D. Haw. 2000).
- 27 Felix v. Cayetano, No. 93-00367DAE (D. Haw. September 13, 2002)(on file with authors).
- 28. Cordero v. Pennsylvania Dept. of Educ., 795 F. Supp. 1352 (M.D. Pa. 1992).
- 29. For example, the functional behavioral assessment and positive behavioral interventions and supports mandated by the IDEA for children who evince problem behavior in school. Decisions affirming children's entitlement to these services are described in *Suspending Disbelief: Moving Beyond Punishment to Promote Effective Intervention for Children with Mental or Emotional Disorders*, Bazelon Center for Mental Health Law, May 2003. Available via www.bazelon.org/issues/children.
- 30. Exhaustion requirements under IDEA also make it difficult to combine other statutory claims for an individual child. See 20 U.S.C. § 1415(l).
- 31. Tredyffrin/Easttown Sch. Dist., 33 IDELR ¶ 254 (SEA PA 2000).
- 32. 20 U.S.C. §1400, *et seq.*; 34 C.F.R. §300.300, *et seq.* "[P]arent counseling and training" is defined as "assisting parents in understanding the special needs of their child and providing parents with information about child development." 34 C.F.R. § 300.16(b)(6). See also with regard to parent counseling, 34 C.F.R. § 300.16(b)(8)(v), (12)(ii) and (iii), and (13)(v).
- 33. San Lorenzo Unified Sch. Dist., 26 IDELR 331 (SEA CA 1997).
- 34. Belcherton Pub. Sch., 26 IDELR 961 (SEA MA 1997). See also Bd. of Educ. of the Portage Pub. Sch., 23 IDELR 667 (SEA MI 1995)(ordering school to pay for family counseling so family could "gain a better understanding of how [the child's] abilities and disabilities will impact him in the future and how the education he is provided now must be directed toward this end"); New Prairie United Sch. Corp., 30 IDELR 346 (SEA IN 1999)(ordering the district to pay for twice monthly family counseling sessions including travel to/from out-of-state residential facility, as recommended by a mental health clinician, because therapy was necessary for student with autism/Asperger's disorder to receive FAPE); In the Matter of T., 32 IDELR ¶ 219 (SEA CT 1999)(awarding residential placement with group, individual and family therapy to student with SED because psychologists found that student's emotional difficulties significantly affected her education).
- 35. Burlington Sch. Comm. v. Massachusetts Dept. of Educ., 471 U.S. 359 (1985).
- 36. San Juan Unified Sch. Dist/Sacramento County Mental Health, 28 IDELR 47 (SEA CA 1997).
- 37. Krichinsky v. Knox County Sch., 963 F. 2d 847 (6th Cir. 1992).
- 38. Seattle Sch. Dist., 16 EHLR 1091 (SEA WA 1990). See also St. Tammany (LA) Parish Sch. Bd., 31 IDELR ¶ 144 (OCR 1999), in which the Office of Civil Rights (OCR) failed to sustain a complaint against the school district for failing to provide in-home family therapy and behavioral management for a student wit multiple disabilities, including autism, because the child's IEP did not call for them. This action was brought as a complaint before the U.S. Dept. of Education's OCR as a Section 504 claim, not as an IDEA claim. From a strategic perspective, however, it illustrates the importance of effective advocacy during IEP development.
- 39. *In re Child with a Disability*, 21 IDELR 753 (SEA CT 1994).
- 40. Taunton Pub. Sch., 27 IDLR 108 (SEA MA 1997).
- 41. Burke County Bd. of Educ. v. Denton, 895 F. 2d 973 (4th Cir. 1990).
- 42. Hunger v. Leininger, 15 F. 3d 664 (7th Cir. 1994).
- 43. *Metropolitan Sch. Dist. of Lawrence Township*, 36 IDELR 282 (SEA IN 2002). The outcome of this case, like many IDEA cases, may have affected by the school district's extreme neglect—i.e., inappropriately leaving the student in homebound placement for two years.

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- 44. San Lorenzo Unified Sch. Dist., 26 IDELR 331 (SEA CA 1997).
- 45. East Windsor Bd. of Educ., 20 IDELR 1478 (SEA CT 1994). See also, under Extended Year Services below, Margate City Bd. of Educ. (the outside recreational program was denied during the summer because the school provided an alternative summer program that the hearing agency ruled was adequate, and based on the higher standard required for ESY services); and Dracut Public Schs. (student granted payment for recreational daycamp to address his self-esteem during period that school did not provide ESY services).
- 46. Medford Pub. Schs., 27 IDELR 1020 (SEA MA 1998).
- 47. 34 C.F.R. § 300.309(a)(1).
- 48. See 64 Fed. Reg. 12406 at 12575-12576. See also, 34 C.F.R. § 300.309(b)(2).
- 49. The regulations cite several cases as establishing these higher standards, including: *Johnson v. Bixby Indep. Sch. Dist. No. 4*, 921 F. 2d 1022 (10<sup>th</sup> Cir. 1990); *Crawford v. Pittman*, 708 F. 2d 1028 (5<sup>th</sup> Cir. 1983); and *Georgia Ass'n of Retarded Citizens v. McDaniel*, 716 F. 2d 1565 (11<sup>th</sup> Cir. 1983).
- 50. Margate City Bd. of Educ., 35 I.D.E.L.R. 57 (SEA NJ 2001).
- 51. Dracut Public Schools, 35 IDELR 134 (SEA MA 2001).
- 52. Brent v. San Diego Unified Dist., 25 IDELR 1 (S.D. Calif. 1996). In another ESY case, a class of parents filed a complaint before the OCR, seeking to have the district reinstate its ESY communication and social-skills program on the grounds the program's elimination violated the rights of children with autism and related disorders under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. The OCR and the district agreed that the district would reinstate the program until it could provide an appropriate alternative. Greenwich (CT) Pub. Schs., 34 IDELR 69 (OCR 2000).
- 53 A thorough analysis of this topic is beyond the scope of this paper because of the volume of cases.
- 54. Giliberti, M. & Schulzinger, R., Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs. Bazelon Center for Mental Health Law (March 2000).
- 55. Burlington v. Department of Educ., 471 U.S. 359 (1985).
- 56. Board of Educ. v. Rowley, 458 U.S. 176, 206-07 (1982).
- 57. O'Toole v. Olathe Dist. Sch. Unified Sch. Dist. No. 233, 144 F. 3d 692, 707-08 (10th Cir. 1998).
- 58. Hall v. Shawnee Mission Sch. Dist., 856 F. Supp. 1521, 1530 (D. Kansas 1994).
- 59. San Diego v. California Special Educ. Hearing Office, 93 F. 3d 1458 (9th Cir. 1996) at 1467 (citing Clovis Unified v. Office of Administrative Hearings, 903 F. 2d 635 (9th Cir. 1990)). See also Kruelle v. New Castle County Sch. Dist., 642 F. 2d at 693 (basing decision on determination of whether residential placement is "necessary for educational purposes, or . . . a response to medical, social or emotional problems that are segregable from the learning process); North v. District of Columbia Bd. of Educ., 471 F. Supp. 136 (D.D.C. 1979)(adopting intertwined test).
- 60. See, e.g., *Mrs. B. v. Milford Bd. of Educ.*, 103 F. 3d 1114 (2<sup>nd</sup> Cir. 1997); *Kruelle v. New Castle County Sch. Dist.*, 642 F. 2d 687 (1981); *California Special Educ. Hearing Office*, 93 F. 3d 1458 (9<sup>th</sup> Cir. 1996).
- 61. CSan Diego v. California Special Educ. Hearing Office, 93 F. 3d 1458, 1462 (9th Cir. 1996) at 1464.
- 62. Id., at 1468.
- 63. Sometimes costs are divided into educational and medical costs to be apportioned among the parties. See, e.g., *Drew P. v. Clarke County School Dist.*, 877 F. 2d 927, 929 (11<sup>th</sup> Cir. 1989)(costs of residential placement apportioned between school district and parents); *Doe v. Anrig*, 651 F. Supp. 424, 430-32 (D. Mass 1987)(costs apportioned between school district and father). The Supreme Court ruling in *Cedar Rapids Community Sch. Dist. v. Garret F.*, 526 U.S. 66 (1999), may have resulted in greater allocation of non-educational costs to school districts to the extent the apportionment is based on a "medical" versus "educational" distinction.

- 64. Mrs. B., 103 F. 3d 1114 (2<sup>nd</sup> Cir. 1997) at 1121.
- 65. Id.
- 66. Seattle Sch. Dist., No. 1 v. B.S., 82 F. 3d 1493 (9th Cir. 1996) at 1497.
- 67. Id., at 1498.
- 68. Id., at 1501 (citations omitted).
- 69. See, e.g., *Kruelle*, 642 F. 2d at 695 ("before ordering residential placement, a court should weigh the mainstreaming policy embodied in the [IDEA]").
- 70. Lenn v. Portland Sch. Committee, 998 F. 2d 1083 (1st Cir. 1993) at 1085 (progress had "slowed to a crawl" for two school years and the student was two years behind in reading and six years behind in math).
- 71. *Id.*, at 1086 (citing Abrahamson v. Hershman, 701 F. 2d 223, 227 (1st Cir. 1983); accord Hampton Sch. Dist. V. Dobrowski, 976 F. 2d 48, 52 (1st Cir. 1992).
- 72. Mrs. B., 103 F. 3d at 1119.
- 73. Muller v. East Islip Union Free Sch. Dist., 145 F. 3d 95 (2nd 1998) at 100.
- 74. Reiman v. Waynesville R-VI Sch. Dist., 36 IDELR 265 (W.D. Mo. 2002).
- 75. North v. District of Columbia, 471 F. Supp. 136 (D.D.C. 1979) at 140.
- 76. Id.
- 77. As previously noted, this report cannot substitute for legal research. Because of the ongoing nature of the litigation, this information may become incomplete after the date of publication.
- 78. Additional cases that may be useful for policymakers and advocates seeking access to comprehensive mental health services under Medicaid include:
- *D.R. v. Concannon*, No. 90-483 DA (D. Or. 1991) (requiring the state to promptly provide medically necessary behavioral health services for children who previously have been screened and found in need of such services);
- *Kirk T. v. Houstoun*, 2000 WL 830731 (E.D. Pa.)(finding state was not providing behavioral health services in a timely manner), *sub nom. Delong v. Houstoun*, 2000 WL 1689077 (E.D. Pa.). (refusing to dismiss claims asserting that the state's failure to provide waiver services violated "reasonable promptness" requirement and the failure to use the full 3,382 waiver slots violated the "in effect" requirement);
- Scott v. Snider, No. 91-CV-7080 (E.D. Pa. 1992) (EPSDT case for all conditions and services; a settlement required outreach, complete screening, increased participation in EPSDT program, and expanded services);
- *Visser v. Taylor*, 756 F. Supp. 501 (N. Kan. 1990) (holding that the state violated Medicaid by refusing to provide clozapine to an adult who needed that specific drug);
- Bond v. Stanton, 655 F. 2d 766 (7th Cir. 1981) (holding that Indiana did not sufficiently define the content of the screening package to ensure that needy children receive the thorough screening intended by Congress);
- Tallahassee Memorial Regional Medical Center v. Cook, 109 F. 3d 693 (11th Cir. 1997) (requiring the state to pay for inpatient psychiatric care for adolescents even when such care exceeds the medically necessary time period when the state has failed to provide less restrictive placement due to funding constraints or bureaucratic hurdles);
- *Collins v. Hamilton,* 231 F. Supp. 2d 840 (S.D. Ind. 2002) (requiring the state to provide long-term residential treatment for children for whom the treatment has been determined medically necessary by EPSDT screening); and
- *Salazar v. District of Columbia*, 938 F. Supp. 926 (D. D.C. 1996) (finding that D.C.'s general EPSDT program failed to comply with requirements for informing, screening, follow-up treatment, scheduling and transportation assistance, and due process).
- 79. Larry K. v. Snider, No. 91-680 (E.D. Pa. January 6, 1993).
- 80. Emily Q. v. Belshe, No. 98-4181 WDK(AIJX) (C.D. Cal. May 27, 1998).
- 81. Emily Q. v. Belshe, No. CV-98-4181-WDK (C.D. Cal. Feb. 24, 1999).

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- 82. Emily Q. v. Bontá, 208 F. Supp. 2d 1078 (C.D. Cal. 2001).
- 83. *French v. Concannon*, No. 97-CV-24-B-C (D. Me. July 16, 1998). The Bazelon Center provided technical assistance in this case and can provide information and pleadings to advocates interested in replicating it.
- 84. *J.K. v. Dillenberg*, 836 F. Supp. 694 (D. Ariz. 1993)(decision on early motions for summary judgment and to dismiss the lawsuit). The case is now known as *J.K. v. Allen*. Subsequent interim settlement agreements are on file with the authors.
- 85. J.K., 836 F. Supp. at 699.
- 86. The panel was directed by Dr. Ivor Groves and the other members were Narrell Joyner and H.G. Whittington. Dr. Craig Anne Heflinger also provided valuable assistance to them.
- 87. The principles are available online at www.bazelon.org/issues/managedcare/jk/jkprinciples.html.
- 88. See, e.g., Note of Sanity: Pilot Program Serving Mentally Ill Children Has Proven its Value and Survived, *Arizona Republic*, Feb. 25, 2003.
- 89. *John B. v. Menke*, No. 3-98 0168 (M.D. Tenn. Feb. 25, 1998)(consent decree on file with authors).
- 90. 176 F. Supp. 2d 786 (M.D. Tenn. 2001).
- 91. *Christopher B. v. Premier*, No. 97C-1818 (Circuit Court for Davidson County) (second amended complaint filed May 26, 1998).
- 92. Metts v. Houston, No. 97-CV-4123 (E.D. Pa. Mar. 27, 1998).